University of Salford
A Greater Manchester University

Centre for Nursing & Midwifery Research

A report on the Health and Social Care

Listening Event

April 7th 2011

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Acknowledgements

We would like to thank the busy members of the public and professionals from voluntary, statutory and other services and organisations who gave up their time to share their thoughts and ideas at the Listening Event. Thank you in advance to those who volunteered to work with us further in addressing many of the issues raised in the coming months. Views of participants will greatly help us to make improvements to health and social care student learning, enhance community engagement by the University and inform research, innovation and enterprise in relation to health and social care.

Grateful thanks also to our presenters who got the day off to a good start by sharing their knowledge and experiences of activities at and with the University of Salford.

PART 1

Introduction

The purpose of the day was to enable a wide range of people, including professionals working in statutory, voluntary and other organisations and members of the public, to 'have a say' about health and social care and what we as a University can do **for** and **with** these partners and the public.

We particularly wanted to hear about key concerns of the University such as:
- Strengthening community engagement and partnerships
- Health and social care training we should be providing, for whom, and how this is delivered
- Ideas relating to the University themes including media, use of space and buildings, human rights, social justice and security
- Research topics we should be addressing

However the main strength of the Listening Event approach is that topics for discussion are mostly led by participants who attend. On this occasion, the discussion topics were very much focused on the concerns of participants and lots of information and ideas were generated. The task now is for the event planning team to review the discussion notes and identify what can be addressed and how, in the short, medium and long term. This planning will be taking place over the Autumn in 2011, and any participants or readers of this report are more than welcome to get in touch to work with us or add their views.

The purpose of this report is to record all discussion summaries for sharing amongst participants and others. It is important that participants especially get to read what others had said at the event. The report will lead to changes in University practices such as the content of some of our courses and new business ideas and relationships will also be explored. The event itself provided a useful means of public engagement that others may wish to adopt.

Listening Event Lead Dr Tracey Williamson T.Williamson@salford.ac.uk or telephone 0161 295 6424

PART 2

Event format

To be most effective, the Listening Event was held in spacious and comfortable surroundings, in this case at the Innovation Forum on Frederick Road, Salford M6 6FP. This flexible venue allowed for lots of group discussions at the same time in a main room holding sixty people. Acoustics in the room were good and there was space for easy movement between discussion tables and around flip chart stands next to each table.

The day began with an introduction and presentations to set the scene (see below)

Event programme:

9 15 - 10 00 Registration

10 00 - 10 10 Chair's Welcome, Dr Tracey Williamson, Research
Fellow Public Engagement/User Involvement in
Research

Research and Innovation video (see
http://www.research.salford.ac.uk/video)

**10 10 - 10 15 Welcome from the School of Nursing &
Midwifery**, Dr Nick Hardiker, Research Centre
Director

10 15 - 10 25 Engaging with and by the University,
Linda Richings, University Community Engagement
Manager

10 25 - 10 35 Experiences of being involved in research,
Elaine Jones and Joan Brogden, Independent
Researchers

10 35 - 10 45 Engagement in the School User Carer Forum,
Barbara Allen and Vera Shaw

10 45 - 10 55 Joint project working,
Chris Dabbs, Chief Executive, Unlimited Potential

10 55 - 11 05 Questions

11 05 - 11 15 Purpose & format of Discussions

11 15 - 11 55 <u>Discussions 1</u>

11 55 - 12 00 Flip chart viewing/topic suggestions

12 00 - 1 00 Lunch

1 00 - 1 10 Welcome back. Intro to Discussions 2

1 10 - 1 50 <u>Discussions 2</u>

**1 50 - 2 00 Movement time and flip chart viewing. Intro to
      Discussions 3**

2 00 - 2 40 <u>Discussions 3</u>

2 40 - 3 10 Tea/Coffee and flip chart viewing

3 10 - 4 00 Main group discussion/action planning/evaluation

4 00 FINISH (Tea/Coffee available)

Possible topics for discussion at each of the three discussion sessions were suggested by the facilitators but participants quickly generated their own topics and these were then allocated a table and participants interested in a particular topic, joined that table. A facilitator and a note taker were appointed and following introductions, each topic was explored and notes made on a flip chart. These were then displayed on the walls of the main room for all to read during refreshment breaks. Consent was given for photographs (see next page). The day ended with suggestions by participants about how to act upon what was heard.

In terms of participants, a wide cross section of current and future contacts/partners were sent invitations to take part along with a request to forward these to other interested people or organisations. Therefore the participants were self-selecting. It was voluntary whether groups wanted to disclose who was present in the discussions and where noted these have been included in this report. An overview of attendees is given here to illustrate the mix of participants:

Various members of the public representing themselves e.g. 'lay' researchers and staff/public volunteering or working for organisations such as Talbot House Support Centre; PiC National Training Centre; Expert Patient Programme; Stroke Association; LINk in Salford; Griffin Care Limited; Manchester Beacon for Public Engagement; Princess Royal Trust Salford Carers' Centre; Unlimited Potential; Bury Samaritans; St George's Resource Centre; SALFORDM3 Magazine; Trafford Carers' Centre; Age Concern; the University of Salford (Nursing, Midwifery, School User Carer Forum); NHS Salford; Wigan Council; Manchester Mental Health and Social Care Trust, Salford Health Improvement; Bury Hospice etc.

The event evaluated very well with many comments about how much community engagement was going on with the University and how friendly and approachable University staff were. Participants felt 'house rules' would have been helpful and also clearer objectives for the discussions at times. Suggested improvements centred on a small number of access issues which we will address in future. Many participants said they made useful contacts on the day and took away actions for themselves as a result.

"View of the University has changed – impressive to see openness."

"Confirmed that Salford is an especially good responsive university. The approach worked well – thanks to the manner and forbearance of facilitating staff."

" View of the University has improved. I didn't know so much was going on."

"Very good – good networking opportunity to establish links with health and social care."

"Event worked very well indeed and I was absolutely amazed at how much I learned."

"Very valuable. Met a number of people who have given me information and been able to meet new people."

"Different groups well facilitated – lots of interesting ideas generated discussions from individuals."

"Worked very well – I liked having mixed groups around the table to bring different perspectives."

"I work at the University but I was able to network very effectively."

"Good for networking and awareness of local scene."

PART 3

Overview of what was heard and next steps

Several discussion topics were established by participants and explored during 40 minute sessions. These were:

- Fibromyalgia
- Communication
- Happiness
- Happiness and wellbeing
- Challenging universities
- Research
- Involvement in research
- Research agendas
- Volunteering
- Public health/health promotion/waste
- Post Traumatic Stress (PTS)
- User and carer engagement in education and development
- Social enterprise
- Engaging seldom heard groups
- End of life care
- Miscellaneous

Holding a Listening Event is the easy bit! What happens next is that the event team meet with each other, as well as some participants from the event who have expressed a wish for continued working on a topic. We will also engage with others who can help us to take issues forward. This process will take many months but we expect in a year's time to have made significant progress with many of the issues and we will do our best to locate former event participants and update them on progress. We will also put an update on the University web pages within the 'public engagement' section of our new School of Nursing, Midwifery and Social Work.

In the meantime, several ideas stand out as ones which as a University we can address quite quickly and this will be done. In particular several suggestions were made of topics which we can include in our education programmes for nurses, midwives and others and explore as research topics. Examples are:

- Incidence, experience, management, evaluation of interventions for Post Traumatic Stress; fibromyalgia
- Happiness and relationship to health, quality of life
- Role of technology in promoting isolation
- Accreditation for members of the public for engagement activities
- End of life care training
- Non-traditional placements for students with communities
- Community engagement in research – opportunities, mechanisms
- Patient views and experiences of health related services

- Accessibility of sport and leisure
- Volunteering – skills development and employability
- Public health – audiences, mechanisms and media
- More representative engagement of public in education programmes
- Integrated public involvement across teaching and research
- Social enterprise development
- Seldom heard groups – changing perceptions and engagement in research
- End of life care – preparing practitioners and the public

PART 4

Discussion summaries

The following section sets out summaries of each group's discussions. These were made onto flip charts during the discussions and are reproduced here almost word for word and in the same layout as used by participants. These summaries will be worked on closely by the Listening Event team who will be taking ideas and suggestions forward.

<u>Fibromyalgia</u>

- Reiki

- No of people in Salford sufferers

- Angel Centre - Communication !! Poor for sufferers

   ? Set up intervention centre – once discharged from traditional therapists

- Evaluate most beneficial interventions

- Centre would offer different treatments
        Eg massage/Reiki

- ? Links with Angel – Healthy Living Centre and therapists.

- Sufferer in group had not heard of it

- ? Vit B2

Communication

- <u>User-led</u> groups in Salford want to amalgamate – approx 12 groups

- Collective model

- <u>LINKS</u> – should be connected to all voluntary groups.
    3 groups in Salford – alternative treatment …

- BlueSci – Energise – Angel.

- <u>Website</u>? – all groups contact to keep up to date re services and opportunities.

- Bury – 'PRIDE' projects
    Different Carers and H/C groups – findings were that a Directory required.
    Marketing/advertising v expensive

- Cost and keeping updated directory difficult

- Need dynamic system that is kept up to date

    ASK SID – Salford Information Directory

- Central port of contact for different conditions – As per McMillan nurses/service

- <u>One-stop-shop</u> very useful

- University could act as as conduit – engaging Community and empowering groups to share and control information

Happiness 1

- Barriers/stigma/bullying/poor motivation

- Difficult to quantify

- Lead to isolation

- Parental training

- Training for teachers

- Who would deliver training?

    Partnership working
- Uni
- Schools
- Youth groups
- Drama groups
- Media

- Importance of Leisure and Social Activity

- In happiness and quality of life

- Support network provided by Gateway Club

- How do we engage people to help them see their 'purpose'/potential

- Swimming groups for LD –
    Do people want separate groups or
    Do they want to integrate?

- Self advocacy group – professional assumption to carry out activities in integrated fashion

- However people value segregated groups

- 6 wk course – <u>EXPERT PATIENT PROGRAMME</u>
    Run by PCT (? Now Acute)

- Voices of smaller groups need to be heard/recorded/recognised to enable support mechanisms

- Also recognise certain individuals would not benefit or appreciate targeted groups. (stroke example – long-term hospitalisation)

- Look into possibility of groups paying for their services –
    Motivation for support and running the groups

<u>Students</u>

- 2 – way reciprocation between students/University and Healthcare and group settings

<u>End of Life Care</u>

- New way of training as quite a large gap

- Also isolation and giving people purpose

- Technology can lead to isolation!

<u>Happiness 2</u>

- Happiness and wellbeing strongly linked
- Happiness is person centred
- Finding what a person wants
- What if a person doesn't know what they want
- Older people isolation/stress
- Importance of being listened to
- Create community spirit
- Adopt a neighbour
- Understanding what makes a person tick

Happiness and Wellbeing

Learning Difficulties Partnership Board

Ann-Marie Dillon – LDPB rep
Sean Dempsey – LDPB rep
Linzi Brook – UDW scc
Helen Franks – Uni

If you are happy: Some people need to learn more
                                       about these areas – there are groups/
                                       courses that can help
                                                    But not enough

- Enjoy different parts of life
- Doing more for self
- Getting out more   chat
- Meeting new people   comfort & support
- Living with partner
- Friendship
- Relationships – exciting, difficult. Sharing the good times and the bad.
  Strength in the partnership

- Being in control of own life - lots of people with learning difficulties do not have these
  opportunities.

- Leisure
  Lots of difficult activities to choose from   People in groups mostly nice
                                                          and welcoming
                                                Sometimes a bit unfriendly though

     Benefits include improved!
- Physical health
- Mental wellbeing
- Intellectual stimulation
- Relationships and friendships and meeting new people
- Could be supported (eg Gateway Club) – different views as to whether there
                                                should be specialist/segregated
                                                Groups or not.
- Fun!

  Still accessibility issues at many leisure venues (pubs, clubs, fit cities etc)

Some areas feel too scary to walk about in

Bullies   Training for Parents
                                           Training by people with LD
                                           Anti bullying training

Kids can
be   - name calling, funny looks
intimidating   Parenting
asking you to   - mostly kids but the mum's (she should tell them) don't do
buy cigs and booze   anything about it

<u>Challenging Universities</u>

'Experts' and Changing Goal Posts

Participants: Ellen, Jackie, Vera, Sue, Sue, Lauren

Defining Expertise

Ryan Giggs – Honorary Doctorate

APEL/Credit System from Salford University & carer involvement

Training to be given and counted 'Academic credit', Portfolio credit

Flexible approach to education process

Student Training and Content

Changes in the educational structure

End of life management

Euphemism – Hidden discourses hide dying and death

Communication skills / patient stories is a suggestion

Extra-curricula training

Practical/Vocational training

Intense introduction

<u>Research</u>

<u>Link</u> – GP's   ) Costs – Service delivery
        PCT's)

How to capture voice of concern

        Research   Interact with university

<u>Champion</u>   regular meetings

            Carers
                            Feeding back -
Local needs –
                    Doing research with – training people <u>to do</u> research
   Local groups/carers
                University as a <u>conduit</u>

                    As a fact finder

                    As an 'empowerer'
A 2 way flow
                University is a business

            Open systems to support community groups

        Building capacity

Involvement in Research

Participants: Joan Brogden, Chris Guthrie, Rachel Martin, Jacqui McKenna, Sue Fisher, Elaine Jones, Jeanne Lythgoe, David Britt, Marisha Palm, Laura Seppala

    Involve – Active   Engage

Moving from being told to being asked

Sensitive Training

Clarity of what it's all about

Motivation – Topic triggered   Purposeful occupation

                  Research – continued IT

Active outreach on our part

Widening participation from Health & Social care to other areas

Matching characteristics
         Outsiderness   (Not known to participant)

Payment – For being co-researcher
- And as advisor on steering group
- Teaching

Integration in education and research whole gamut

All has to be   CHOICE   1

MEDIA CITY – Can they help?
    Communicating with 'Not known about'

       ↓

Megaphones?

Silo – Why won't people access services
        If its 2 mins away – "is it cultural"?

        Or is it

Inequalities – 3rd generation unemployment?

Can we find a "shared and common approach"?

Research Agendas 1

Uni researching <u>with</u>

Topics　　　　　　　GP opening

　　　　　　　　　　　　　　access to NHS dentist

Community Groups　　　　　　　　　↓
　　↓
Engaging with big players　　　　topical and common

　　　　　　　　　　　　　　funded

　↓　　　　　　　　　　↑　　↑
　　　　　How to access/find out　　hard to reach

Use of advocates to help /　　　　　　　Suggestions for research
The champions 'v' distancing　　　　　　pooling the ideas
from patients.

What's meaningful?　　　　　　　　　Joined up research
What is 'well being'?
Avoiding the tickbox/tokenistic

　　　　　　　　↔

<u>Link money to commission</u>　　link with PCTs　　　　<u>Big listening survey</u>

3 projects a year　　　　　　　　　　　　↑　　　↑

　　　　　　　　　　　　　　Health　　Big consultancy

Asking what people want to be researched　　Committed to act on the research

<u>Who controls the Research agenda ?</u>

Researchers: - What they are interested in

　　　　<u>Funding</u>　　　　PPI initiative

　　　↑　　　　　　　Drives

　　　　　　　　<u>Problems</u>
　How do we access
　Funding?　　　　↓　　　　　↓
　　　　　<u>have</u> to be　　need to fund
　　　　　attached to a　experienced
　　　　　University　　researchers.
　　　↑

Having the 'name/credibility' / reputation

<u>Research agenda</u>

How do we influence the people with the influence?

Engage people in research - advertise
                                         - be prepared to listen

- Advocacy service in learning disability needs further funding –
  What happens to these services?

Research Agendas 2

Relevance of Salford population to others
- National networks
Pilots – attract interest
  Build a research idea
                            could be topic specific

Ideas **'dump'**   for research topics   ↑

NW People in Research Forum –   other forums

- Putting people in touch with research
- Contact list

- Dump and bigger players → database
- " to raise awareness of benefits of users/carers/in research"

- How to advertise this.

                        What drives these
Champions
                        Conflicts

Community champions)
)   Uni can facilitate
University champions   )

What happens to ideas that can't   transparency
be taken forward

What is Salford community?   what are the areas?

            broadening from the community

    What is local?
                        greater area
                        national agenda
                        feeds into local

Post-Code Lottery

- Service evaluation

Diversity –

Unhappy with maternity closures – on excellence

Local impact –

Survey of key concerns re local service

Access to local services

Dignity and respect

Returning to work

Outcomes -   arise out of

Patient reported outcomes   in patient form

Supporting people –

<u>Volunteering</u>

Participants: Alison Hill, Kathy Jones, Harold Kershner, Karen Davies-Linihan (Bury Hospice), Sue Fisher, Elaine Ball, Barbara Allen, Sean Dempsey (Salford Being Heard)

Role of University – facilitating
Passion – motivation – personal
Opens doors/skills development
Paid/unpaid?
Volunteers offer "so much more"
↓
Perceived as unskilled (?)
Financial constraints on opportunities
Need to create a 'valued/professional' profile for volunteers
Need for training, support, reciprocity, friendship, partnership,
demand, competition, share volunteer skills

Student volunteers' skills, interests need to be identified/matched with opportunities available
Placements – what is 'local' e.g. Salford/Bury
Volunteers with Learning Disability need specific training to successfully volunteer
Will 'cuts' impact on volunteering opportunities?
Raise awareness of groups
Volunteering a two-way process
Organisational support needed (Hospices)
Challenge: how to change perceptions

Public Health/Health Promotion/Waste

Participants:
Anna – HIS, Lauren – George House Trust, Anne Marie – Salford – <u>Being</u> heard and
Partnership, Linzi Brook – Development worker for people with LD's
(Salford City Council), Laura – PHD student Salford Uni

Salford – HIV – 2nd largest incidence in....
Large gay community (Georgetown)
Large African population – asylum seekers   (Lauren)

<u>Social Marketing</u>

- Getting message across – how?
- Targeting messages to certain groups
- Department of Health information regarding social marketing   (Anna)
- Communities that don't read
- Oral dissemination of information
- Not only people with Learning Difficulties who don't read   (Linzi)
- Computers can give headaches – even if you can read!
- Would prefer to be written to
- Breast screening etc – letters not often clear
- Carers who receive information may throw it away because they think it is not relevant
- Sexual advice given in sheltered accommodation – information passed through 3rd party
  (Anne Marie)

- Media scaremongering
  Autism / MMR   (Linzi)

- 80's and 90's media scare re HIV and AIDS – stigmation re testing.
  No media coverage to promote testing   (Lauren)

  Information required to make informed choice   (Anna)

  HIV +ve babies – education not given to those from outside UK. 2 years testing after
  baby born. Can be transmitted via breast milk   (Lauren)

- Recycling on streets / middle of towns

- Litter big problem
- Bad attitude in UK
- Education re attitude to waste – <u>schools,</u> <u>Universities</u>, TV? Media   (Laura)
-
- Dog muck
- Signs – fines £50 - £100
- Humour in messages   (Linzi)

- More positive approaches to public health as opposed to 'finger wagging'. (Anna, Linzi)

- Egypt – unemployed man went out and picked up litter in whole city

  Ripple effect.
- Bottle return schemes – pennies for returns   (Laura)

Post Traumatic Stress

RECOGNISING THE 'REAL' PROBLEM

SAFETY NETS/HELP – WHEN PROFESSIONAL NEEDED

WHAT IS 'TRAUMATIC STRESS' ?

THE DEFINITION

SUPPORT OF FAMILY AND SIGNIFICANT OTHERS

CENTRE FOR DISTRESSED PEOPLE

- REGAIN A SENSE OF PURPOSE
- SUPPORT IN SAFE ENVIRONMENT

FIBROMYLGIA – RESEARCH RE PEOPLE IN SALFORD – SUE
     -
TRAUMA

User and carer engagement in education and development

Participants: Rahila Ahmed, Keith Ivison, Hannah Stephens, Terry Holland, Joanne Parker, Elaine Ball, Lauren Rowe

Representative user and service Involvement mechanisms.

Student training include   Needs of communities with protected characteristics, communications, Barriers etc.

Samaritans – key issues presentations/training packages.

Explore mental health and carer issues

Immerse in community – Experiential learning

Community Empowerment to form solutions (Ensure initial ownership)

Social Enterprise

Participants:
William Finch, Dave Griffin, Sam Griffin, Harold Kershner, Chris Dabbs, Joan Crook, Linzi Brook, Sean Dempsey, Jade Hanratty, Nick Hardiker

- HOW?

- NEW WAYS OF THINKING (not like a Local Authority)

- S.E. IS ONLY ONE MODEL.

- DIFFERING SKILLS SETS

- DRIVERS

- RESOURCES

- HOW TO INVOLVE PARTNERS?

- SPIN OUT SOCIAL ENTERPRISE

  How can Salford University assist in placements for Day Centre Users involved in the world of work?

  Setting up a social enterprise
  Moving away from Local Government thinking and mind set
  Involvement – how wide is the level of inclusion?
  Define values and mission statements
  Can the Local Authority run a 'social enterprise'?
  There are already some in place – leisure trusts and housing associations
  Mutual information services set up by Co-ops
  Chris will send through a list of organisations helpful in setting up social enterprises
  Wigan are finding initial interest from academic organisations but they are not seeing it through to fruition
  Chris suggests moving away from Local Authority Business Plan model to a 'vision'; or 'dream' and outlining social outcomes
  Is a charity .... feasible
  Some are better than others
  Salford University may be able to provide advice and support and their payback is good PR, volunteering opportunities and research opportunities
  How can people with learning disabilities access sport and leisure activities?

Seldom Heard Groups

Community	The Group Michelle Howarth
'Why is everyone 'sorry' when a disabled child - frame of mind – Outset – attitudes can –ve influence on future care Everyone saw the condition rather than the person Ways in which this can be communicated Education – No predictions/assumptions Negative assumptions Paternalistic views Stereotypical images Being treated differently People thinking that you won't be able to cope Person centred care University helping hard to reach groups to communicate Lots of different groups doing things separately. Why can't we do something together? One stop contact Not live) Facebook) dual approach Ask SID one stop place for info in Salford (SID = Salford Info Directorate) One stop shop – Talbot house in Manchester Signposting people to the right place Connecting and Communicating 'get out there' go and meet – Walking the walk – Finding out what the problems are. Tapping into the health improvement group. Volunteer sharing scheme is one example Providing contact details – How often do support groups come together and how could they meet?	Jeff – Carer of Marilyn Marilyn Bernie – parent of an adult son with severe learning disability Anne Marie – on partnership board for Salford Anna Onobola – health improvement officer for communicable disease and infection prevention Anne Marie Naseby – Matron at Salford Royal training with children and abuse – also on Salford Partnership Board Sue Fawcett – Community stroke Co-ordinator in Salford has sister with 2 severely disabled children Paulette Holness – Salford Disability Service Clare Wakefield – Sister – Wigan carer issues in own family. Rihala – Learning devel dep for MH Trust. Partner has LD

<u>Education</u> Making placements for students more meaningful and placements that 'engage' with the communities <u>Research</u> – How does the community know what **R** is ongoing in the University? Engaging more with the Uni in collaborative **R**. Are there ways in which user/carers can link with themes? Groups can link in but what about the individual – how does the university engage with the individual? Advocacy – looking at people who can advocate and locate and include the individuals to engage with the community. These people who are not linked into services GPs – but there are those that don't. Some people don't want to be part of groups Not on the radar! – word of mouth vs technology. ?Mediacity – but there are some communities that don't have/listen to radio/TV Closed door community <u>Working in silos</u> – boundaries in Salford – sub-groups, little villages. Cultural and geographical Research – how do we work with cultural boundaries? Different groups. Different approaches. What are the shared and community concerns/issues?	

Parent/Carers Why are professionals sorry! Makes me sorry so I treated them like this.
Need people to see person not problem.

Education Health professionals   Audio info, no predictions e.g. L.D. Strokes.
Poor behaviour – creates sick society, poor assumptions

Research Communication that reaches seldom heard groups

Helpline One bank that holds all info about what's going on. One phone number

Ask SID Salford Information Directory. How do we get to know about this?

We have a resource   Linda

+

Salford Health Improvement

But how do we share this resource

Leaflets   Facebook   'The Valley'

Placements   Wider engaging eg LD Bernie
                   Meaningful   3 medics – 3 nights and days learnt more

How Can   Seldom Heard Groups feed into Research in University
           Sue – Stroke – research – findings – money

How do we engage / access to people from Seldom Heard groups that don't belong to groups

Housebound could university look at advocacy

Not Linked to services but have needs.

End of Life Care

Helen Hills Salford Carer Centre
Barbara Allen User/Carer Group
Jeanie Humphries Salford M3 Magazine
Janet Richardson Nurse Development Manager Trafford Acute (Nurse Educator)
Susan Hinder Carer Development Worker and family – (personal interest)

Who makes the decisions?
After death – supporting the families
How can people find out more without going on courses?
Knowing you don't have to go to hospice or hospital to die
Macmillan – Information pod (narrow end of life spectrum)
Getting people to understand Macmillan is not just about cancer – it's for them too
Everyone should have a good understanding of death/be experts in it as death is coming back to the community/out of hospital
Children being exposed to dying matters – bringing people together
Getting the right information at the right time
How to die well – people think there is a big secret
Comfort, support, confidence
Awareness – How can we improve end of life care?
Importance of spiritual issues

Helen Franks
Elizabeth Collier
Janet Miller RN Clinical TGH Educator
Avril Hackett, NHS Trust Foundation
Public Sector Research Public member
Karen Davies – Linihan RN
Prof development and quality Bury Hospice (education)
Kathy Jones Age Concern Salford (SRH)
(aftercare people >60 who have been through A&E)
(Personal interest/dementia)

As a daughter with older parents I need to know more about what to expect – learning about what I need to know about how to help and how I will cope if the situation arises and how I can contribute to help others

Dying matters wb 3/5/11 talk about death and dying. We need to talk about death – Anger of people who don't want to talk about it

Supporting nurses in giving bad news bigger focus in nurse education - link in to GPs

Gold standard framework and care homes - all aspects of dying
What happens when people trained in this no longer have specialist jobs?
Support from Uni to train other people outside the hospice
Training/education too expensive

Communication re bad news
Social/isolation when people are at home
In inpatient
Uni deliver – training the trainers
How to help nurses who don't have time or money to access help to develop these skills
Information/who are the carers?
Information re what services are available

<u>Miscellaneous</u>

Salford Royal Foundation Trust: Ideas to explore
1. Support setting up a staff forum as successful as yours
2. How to meet equality duties in terms of workforce e.g. addressing imbalance and under-representation
3. Education and Development requirements as listed in CQC Standards
4. Short half day leadership courses/health and social care staff (similar to UCLAN's equality and diversity courses)